

1 A MEMORIAL

2 DECLARING FEBRUARY 28, 2017 "WORLD RARE DISEASE DAY" IN THE
3 SENATE.

4
5 WHEREAS, there are approximately seven thousand
6 different types of rare diseases and disorders, with more
7 being discovered each day; and

8 WHEREAS, thirty million people in the United States are
9 living with rare diseases, which equates to one in ten
10 Americans; and

11 WHEREAS, it is estimated that three hundred fifty
12 million people worldwide suffer from rare diseases; and

13 WHEREAS, if all the people with rare diseases lived in
14 one country, it would be the world's third-most-populous
15 country, according to statistics compiled by Global genes;
16 and

17 WHEREAS, in the United States, a condition is considered
18 "rare" if it affects fewer than two hundred thousand people
19 combined in a particular rare disease group; and

20 WHEREAS, eighty percent of rare diseases are genetic in
21 origin and are present throughout a person's life, even if
22 symptoms do not immediately appear; and

23 WHEREAS, approximately fifty percent of the people
24 affected by rare diseases are children, and thirty percent of
25 children with rare diseases do not live to see their fifth

1 birthday; and

2 WHEREAS, rare diseases are responsible for thirty-five
3 percent of deaths in the first year of life; and

4 WHEREAS, according to the EveryLife foundation for rare
5 diseases, drug treatments have not been approved by the
6 federal food and drug administration for ninety-five percent
7 of rare diseases; and

8 WHEREAS, during the first twenty-five years of the
9 Orphan Drug Act, passed in 1983, only three hundred
10 twenty-six new drugs were approved by the federal food and
11 drug administration and brought to market for all rare
12 diseases combined; and

13 WHEREAS, although rare and genetic diseases, and many of
14 their symptoms, are unfamiliar to many doctors, rare diseases
15 as a whole represent a large medical challenge;

16 NOW, THEREFORE, BE IT RESOLVED BY THE SENATE OF THE
17 STATE OF NEW MEXICO that February 28, 2017 be declared "World
18 Rare Disease Day" in the senate; and

19 BE IT FURTHER RESOLVED that a copy of this memorial be
20 transmitted to Global genes. _____

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